

BIOPOLITICS AND REPRODUCTIVE GOVERNANCE

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“Everything for the Benefit of Man, Everything for the Sake of Man!”¹: Genetic Counselling in Socialist Bulgaria

Abstract: *This paper examines the process of introduction and popularization of genetic counselling and prenatal diagnosis in socialist Bulgaria, and the efforts of human genetics experts to “bring these practices closer to the population”. In keeping with the preventive spirit of the socialist model of public health, these practices were declared to be forms of “prophylaxis” – a term that largely obscures and mitigates the fundamental moral dilemmas associated with the fact that, in this context, “prophylaxis” often meant selective abortion. This practice, with its clear eugenic implications, has long been a focal point of critique from bioethicists, disability activists, and academics. Drawing on both scholarly and popular publications by leading Bulgarian geneticists, as well as on archival documents, the paper traces how this preventive undertaking unfolded, how it was framed by experts, and what images of disability were mobilized to promote these practices and to responsabilize socialist citizens in the sphere of reproduction.*

Keywords: *genetic counselling; disability; selective abortion; socialism; prophylaxis.*

Introduction

Genetic counselling is a key nexus within clinical genetics, serving as an essential part of a decision-making process that is both literally

¹ The full quote reads: “The prophylactic activity of medical-genetic counselling is the fullest expression of the aspiration to realize the call “Everything for the benefit of man, everything for the sake of man!” (Georgieva, 1988: 79).

and metaphorically a matter of life and death. Historically, such decisions primarily concerned an individual's reproductive future – whether to abstain from having children in high-risk situations or to terminate a pregnancy following a fetal diagnosis of disease or disability. However, as advances in genetics have provided an ever-growing wealth of information, the scope of dilemmas and controversies has expanded accordingly. Genetic counselling is now available in cases of presymptomatic testing for late-onset disorders such as Huntington's disease and certain cancers, or when patients need help to navigate the ambiguities generated by unanticipated findings and results of uncertain significance provided by the new genome-wide technologies (Clarke, 2020; Kaneva, Dimitrova, 2023). At the same time, another feature that adds immense complexity to these situations and decisions is the fact that their implications are obviously not limited to ourselves or even to our children – they invoke population-wide images that claim to affect the well-being of future generations. In this sense, genetic counselling is a very peculiar encounter whose stakes can be framed on multiple scales: it is involved both in determining which lives are worth living within individual families and in envisaging grand demographic and public health projects. But whatever the scale, images of desirable and undesirable futures play a key role, and they are negotiated and renegotiated in this seemingly small and intimate setting where genetic and medical information is conveyed.

Central to these images is disability or chronic illness, commonly thought of as a life that should be avoided – one associated with suffering and viewed as a burden on families and societies. Prenatal diagnosis and selective abortion – the most common outcomes of genetic counselling in affected pregnancies – allow this to happen in the early stages of fetal development, reinforcing the conviction that these practices are morally unproblematic. Furthermore, the eugenic rationality underpinning them is effectively concealed by the advent of the new biotechnologies. When this powerful industry is combined with state-sanctioned prenatal and other screening programmes, and this complex is framed as the epitome of autonomous, informed choice and responsible parenting, it becomes especially difficult to challenge. This system operates effectively because it can govern at a distance, beyond constant state surveillance (Rose, 1996; Rose, Miller, 1992), relying on the production of a regime of expanded responsibility for ourselves, our health, and our future. In this regime, the prudent self can “manage its present in the light of knowledge of its own future” (Rose, Novas, 2005: 441-

442). This notion of self-management is often construed as an essential aspect of liberalism and neoliberalization – a multifaceted process in which citizens actively shape and enhance themselves through various practices of self-optimization (Dean, 1999; Rose, Miller, 1992). However, research on reproductive genetics and genetic counselling within the socialist bloc (Schmidt, 2024; Doetz, 2023; Petermann et al. 2017; Dimitrova, 2012) demonstrates that similar technologies of self-governance were being cultivated and internalized in these contexts as well, the purpose being to nudge citizens into directing their choices and adopting lifestyles aimed at managing risky futures.

This paper examines the introduction and enforcement of genetic counselling in socialist Bulgaria, and the efforts of human genetics experts to incorporate these practices into the socialist biopolitical project of optimizing the collective body and cultivating responsible socialist citizens in the sphere of reproduction. The main focus is on the images of disability as the embodiment of an undesirable future that were mobilized to promote genetic counselling, followed – when possible – by prenatal diagnosis and selective abortion. In practice, experts invariably referred to and constructed the profile of a “life unworthy of living”, whose undesirability was never problematized. The normalization of selective abortion was further reinforced by the absence of voices advocating for alternative images of disability. In other contexts, such spokespersons are mainly the communities of people with disabilities and their allies, who struggle for the demedicalization of genetic counselling. However, in socialist Bulgaria, there were no such spokespersons, and this determined the limited epistemic resources available for deciding which lives were unworthy of living.

The paper draws on data from several sources. The most important among them are the monographs, collective works, and articles of socialist experts in genetics, as well as popular pamphlets – such as the series *Talks on Health* [Беседи за здравео] and *The Doctor Advises You* [Лекарят ви съветва] – dedicated to the prevention of hereditary diseases. The archives of the Department of Medical Genetics headed by Maria Tsoneva, her personal archive, as well as the archives of the Scientific Institute of Paediatrics at the Medical Academy and its affiliated clinics have also been studied. Since the main focus of the article is on the representations of disability mobilized in genetic counselling as a tool for responsabilization, the socialist history of the National Genetic Laboratory (NGL) is not addressed in the present analy-

sis. It played important role in introducing metabolic and enzymatic diagnostic methods for the most common inborn errors of metabolism, as well as in implementing mass neonatal screening for phenylketonuria and galactosemia, but prior to 1989 was not involved in genetic counselling.²

In the first part, I will briefly outline the emergence of genetic counselling, addressing the fundamental principles that ostensibly guide it, as well as its critiques – particularly from a disability perspective. The second part focuses on the situation in socialist Bulgaria, where genetic counselling, in line with the preventive spirit of the socialist model of public health, was considered a key component of genetic “prophylaxis” – which often meant selective abortion. I will pay particular attention to how medical geneticists framed the nature, objectives, and broader social role of their work, as well as to the moral imperatives they saw as guiding their practice. Finally, I will conclude by linking the socialist legacy to the postsocialist framing of prenatal diagnosis and selective abortion, and the persistent poverty of epistemic resources regarding living with disability in Bulgaria.

The Moral Anxieties around Genetic Counselling

The term “genetic counselling” was first used by Sheldon Reed, who introduced it in 1947 and later, in 1974, published a book on the early history of the practice. He defined it as “a type of social work intended for the benefit of each family rather than for the state or the population” (Clarke, 2017: 543), aiming to categorically distance genetics and genetic counselling from the legacy of eugenics. For this reason, the so-called non-directiveness was taken as the foundational principle: “an approach to genetic counselling that aims not to guide the patient (or client) to an outcome predetermined by the counsellor or the genetics service but instead to support the patient in reaching their own decisions” (Clarke, 2017: 543). This basic requirement is still valid today, although the transformations in the tasks and tools of medical genetics have made it less relevant in certain fields, such as oncology and cardiology (Clarke, 2017: 541-542). Within reproductive genetics, the principle of non-directiveness stems from the idea that clients should maintain as much autonomy as possible, with the counsellor’s role limited to providing relevant information. However, the ability to achieve this neutrality within the actual encounter and communicative exchange

² This changes after 1989. For a reconstruction and analysis of the more recent history of NGL, see Dimitrova, 2012.

has been the subject of many critiques. Critics point out that when purely medical information about disability is conveyed, it simply cannot be neutral – it is always negative, and even those genetic counsellors who strongly endorse patient autonomy and informed consent nonetheless tend “to present genetic conditions likely to produce a physical or mental disability as biological errors to be avoided for medical, psychological, and economic reasons” (Stern, 2012: 3). Moreover, the counselling encounter itself takes place within a broader medical setting, where “power relations [are] at play” and “medical professionals perpetuate epistemic injustice when they offer their patients distorted [...] or limited information” (Knight, Miller, 2012: 2). Additionally, the very fact that the healthcare system offers prenatal screening for a number of diseases “inevitably conveys a recommendation to pregnant women that accepting the test is the responsible course of action” (Clarke, 2009: 253). Although the discourse around such programmes emphasizes reproductive autonomy and the right to informed decision-making, their very existence conveys this message and normalizes the prenatal elimination of life with disability (Clarke, 2009: 253). Acknowledging these complexities, some genetic counsellors (e.g., Clarke, 2009), disability activists, bioethicists, and disability studies scholars coalesce around the argument that genetic counselling cannot avoid its inherently political nature (Patterson, Satz, 2002). Thus, a persistent collective voice has emerged, highlighting the problematic nature of genetic counselling as – in most cases – a gateway to selective abortion.

Critics, particularly activists and scholars in disability studies, see a fundamental contradiction in the normalization of selective abortion on the one hand, and formal public and legislative demands that claim as their priority the support, integration, and non-discriminatory treatment of people with disabilities, on the other. As a countermeasure, they do not advocate for banning such abortions, but instead propose ensuring that prospective parents receive more balanced information during genetic counselling sessions. This, for example, could be achieved by supplementing medical information with insights into the everyday lives and personal experiences of parents and people living with disability. To put it another way, it would be fair to balance strong ableist prejudices against disability with more information stemming from lived experience. This third approach, sometimes referred to as the pro-information movement, focuses solely on the conditions under which prospective parents make their decisions. As Rob Sparrow (2008)

points out, given the radical nature of the critique of the power structures that determine which lives are worth living and which are not, such demands are more than modest: they call only for the provision of relevant firsthand information about life with disability by those who have actually experienced it. In other words, the reaction is not against the dominant decision itself, but against the way it is made, from which disabled people are excluded (Sparrow, 2008: 122).

Genetic Counselling in Bulgaria: Institutionalization and Problems on the Ground

Within the socialist bloc, the first genetic counselling centres emerged in the second half of the 1960s in Hungary, Czechoslovakia, the GDR, and Yugoslavia. By the end of the 1970s, a network of regional prenatal screening centres was already in place (Schmidt, 2024: 1). In Bulgaria, early interest in genetic counselling seems to have arisen in the context of psychiatry: in 1965, Vassil Milev, one of the prominent Bulgarian psychiatrists, published two articles advocating for the establishment of medical-genetic clinics, arguing that “medical genetics is a science with broad prospects” and that counselling centres would “help integrate [it] into concrete medical practice” (Milev 1965: 123). According to the geneticist Maria Krachunova (1983: 109), the first genetic counselling office in Bulgaria was opened the same year at the Scientific Institute of Neurology, Psychiatry and Neurosurgery, focusing exclusively on mental illness. It is likely that its establishment was driven by Vassil Milev himself, who in his 1974 monograph *Clinical Genetics in Psychiatry* notes:

In this book, we report some of our experience with the genetics of mental illness, acquired over more than ten years of work. This responsible and difficult task was undertaken, it may be said, for the first time, and, in fact, we have remained so far alone. The practical impossibility of exchanging scientific experience and, especially, the absence of opponents with genetic expertise has undoubtedly affected its quality. (Milev, 1974: 7)

Genetic counselling in Bulgaria was regulated by order of the Ministry of Public Health in 1975, following the establishment of the Department of Medical Genetics at the Institute for Specialization and Improvement of Physicians (ISUL) in Sofia by Maria Tsoneva in 1971. In her autobiography, Tsoneva recalls that in 1969, “I was tasked with establishing and organizing [the Section for Genetic Prophylaxis and Population Genetics] at the Centre for Hygiene,” and in 1971, “with

organizing the country's first Department of Medical Genetics at ISUL."³ It is worth noting that her biography contains no elements that could suggest any ideological contradictions in relation to the communist regime. On the contrary, as a high school student, she was a member of the RMS (Union of the Workers' Youth). Because of this, she was expelled from high school and sentenced to 15 years in prison under the Law for the Protection of the State and served time in the prisons of Shumen and Varna. Her memoirs from the time she spent in Varna's prison, as well as the poems she wrote there, have been preserved in the archives.⁴

Her expertise was shaped by specializations on both sides of the Iron Curtain – beginning in 1965, she specialized in Switzerland, the USSR, Britain, Denmark, Sweden, and France. Later, she served as a consultant to the World Health Organization.⁵ In a report on the occasion of Tsoneva's sixtieth birthday, Bratan Bratanov, one of Bulgaria's most eminent paediatricians at that time, stressed that she always possessed "an acute sense of the needs and problems of practical healthcare. This approach is reflected in her views on medical genetic counselling as the highest form of unity between theory and practice in the field of medical genetics. Professor Tsoneva is the most zealous propagandist and organizer of the network of medical genetic counselling centres in our country."⁶

In order to achieve this unity, the research activities of the Department of Medical Genetics focused on "major theoretical problems of medical genetics [that are] of great applied importance for practical healthcare: 1. Research on the genetic status of the Bulgarian people; 2. Research on the factors causing mutations in humans; 3. Genetic polymorphism and its clinical significance."⁷ However, publications and archival materials consistently highlight as the Department's major achievement "its role in the development of new units in practical

³ SA – Sofia, F. 2561, Inv. 1, a. u. 1, p. 1, "Autobiography", May 4, 1984.

⁴ SA – Razgrad, F. 990, Inv. 1, a.u. 7, "Memoirs of Maria Tsoneva from the prison".

⁵ SA – Sofia, F. 2561, Inv. 1, a. u. 2, p. 5, "Autobiography", May 4, 1984.

⁶ SA – Sofia, F. 2561, Inv. 1, a. u. 6, p. 4, "Report on Prof. Maria Tsoneva", May 7, 1984.

⁷ SA – Sofia, F. 2243, Inv.15, a. u. 5, p. 5, "In response to letter number 179, dated March 29, 1983, to the Director of the Scientific Medico-Biological Institute."

healthcare, such as medical-genetic counselling and cytogenetic laboratories.”⁸ In 1984, the Department was tasked with assisting the Maternal and Child Health Department of the Ministry of Public Health in developing Bulgaria’s first national programme and regulatory framework for the establishment of a comprehensive system of medical-genetic consultative care and prenatal diagnosis by 1990. The programme was adopted in 1986. During this period, regulations on pregnancy termination for medical reasons were also updated to include genetic conditions detected by prenatal diagnosis as a “method of prophylaxis of hereditary diseases”, which was introduced in 1983.⁹ In practice, this opened up a completely new horizon for disability governance in the form of selective abortions.

From that moment on, the Department became increasingly involved in counselling and educational activities. In the second half of the 1980s, it actively assisted the healthcare services in the capital Sofia by providing genetic counselling in various hospitals and polyclinics “through the brigades set up for this purpose”¹⁰ and by “actively promoting the achievements of medical-genetic counselling through popular brochures, articles, lectures, etc.”¹¹ Maria Tsoneva emphasized the need for direct contact with communities, urging: “those who can [must] go into the neighborhoods through women’s organizations to give talks, so that it [medical-genetic counselling] will not remain limited to articles and pamphlets. Propaganda work is necessary and useful.”¹² The Department’s Measures for the Implementation of the Decisions of the 13th Congress of the [Bulgarian Communist] Party¹³ set as its main objective “improving the initial identification, registration, and dispensarization of patients and timely referral to medico-genetic counselling and prenatal diagnosis, resulting in a reduction in births of children with malformations and chromosomal diseases – by 1989.” Despite these efforts, in 1990 Maria Krachunova wrote: “In our country, medical-genetic counselling is still not popular enough, and the popular beliefs about its tasks and methods are too incomplete and, to some extent, even wrong” (Krachunova, 1990: 138). Additionally, inadequate

⁸ Ibid., p. 4, “In response to letter number 144, dated March 16, 1983, to the Deputy Director of the Scientific Medico-Biological Institute.”

⁹ SA – Sofia, F. 2243, Inv. 15, a. u. 7, p. 4, “Counter-plan for 1986 of the Collective at the Department of Medical Genetics”, 1985.

¹⁰ Ibid., p. 6.

¹¹ Ibid., p. 10.

¹² SA – Sofia, F. 2243, Inv. 15, a. u. 1, p. 5, “Minutes”, December 19, 1986.

¹³ SA – Sofia, F. 2243, Inv. 15 a. u. 10, p. 19.

prophylaxis coverage was reported, reaching "no more than 30-40% of the country's population needs" (Simeonov, Krachunova, 1993: 17).

Archival documents reveal significant challenges on the ground in terms of resources – staff, materials, and equipment – which made the implementation of wide-reaching and effective activities difficult and dependent solely on the enthusiasm of the twelve members of the Department. Maria Tsoneva undoubtedly stands out as a tireless, disciplined, and demanding leader. Department meeting minutes document her frequent reprimands regarding poor work discipline. As she pointed out, for example, the office for "medical-genetic counselling is often left open and unstaffed [...] it is high time everyone understood that they must stay at their workplace."¹⁴ Another apparently persistent problem was the timely service of patients. Repeatedly, including in the so-called counter-plans (*насрецини планове*), criticism was levelled at the slow return of screening results, which were sometimes delayed by 45 days, and the occasional "failed" laboratory results.¹⁵

The Guidelines for the Activities of the Department of Medical Genetics for the 1986–1990 Period, dated October 25, 1985, provide insight into its resource constraints:

The implementation of the Department's intended activities [...] is directly dependent on the provision of the necessary material and personnel resources [...]. In the first place, the Department lacks sufficient premises [...] the classrooms are extremely undersized and do not meet modern teaching requirements. The conditions in the genetic counselling room are also inadequate. The available laboratories are undersized. We work with chemicals which, due to the unfavourable conditions, cause allergic reactions among staff [...]. It is also essential to secure the necessary amount of chemicals and equipment, especially microscopic equipment, which the Department clearly needs. It has made repeated requests, but has not received a single research microscope suitable for precise diagnostics in years.¹⁶

In addition to these constant shortages, all counter-plans from the second half of the 1980s consistently emphasize the need for cost-saving measures, including reductions in electricity, water, and chemicals usage, and regular submission of recyclable materials.

Even more critical was the shortage of qualified geneticists. In a 1988 letter to the head of the Medical Academy's Education Department, Maria Tsoneva wrote: "To strengthen the front line, we need to

¹⁴ SA – Sofia, F. 2243, Inv. 15, a. u. 4, p. 7, "Minutes", March 22, 1985.

¹⁵ SA – Sofia, F. 2243, Inv. 14, a. u. 3, pp. 20-22, "Minutes", September 23, 1981.

¹⁶ SA – Sofia, F. 2243, Inv. 15, a. u. 8, p. 5.

improve qualifications in [genetic counselling] offices, none of the heads of these offices have a specialty in medical genetics, and some do not even have a clinical specialty.”¹⁷ Immediately after 1989, this issue was further acknowledged: “the training of specialized personnel working in medical-genetic counselling does not meet the requirements of the World Health Organization”, and “the system of personnel training is inadequate [... as they] undergo only one or a few specialized short-term courses” (Simeonov, Krachunova, 1993: 18). In this regard, there is an interesting difference between the Bulgarian and certain Western contexts – particularly the United States. Before the 1970s, genetic counselling there was performed by medical professionals. However, as certified master’s degree programs were introduced, the field began recruiting people without medical training, primarily women (Stern, 2012: 4). This is assessed as the generation that transformed genetic counselling in the United States and turned it into a “feminized health care profession that combines scientific knowledge, empathic communication, and information delivery” (Stern, 2012: 5).

The fact that genetic counselling remained a purely medical activity is pointed out by Susanne Doetz (2017: 412) as a reason for its directive nature in the GDR: “Counselling was performed by physicians or biologists. Thus, counselling had a different focus, and it was not primarily considered a communication process as in the USA, where the client-centered approach of psychotherapist Carl Rogers (1902–1987) had a crucial impact on the practice of genetic counselling.” In Bulgaria – apparently following the same model – any deviation from medical expertise was similarly rejected outright. This is evident, for example, in Maria Krachunova’s 1983 book *Genetics of Mental Illness*, where she references Russian authors who argue that “the counselling physician must be prepared to answer a wider range of questions that are not among their direct tasks: the educational possibilities of children with an inherited defect, vocational guidance, early diagnosis, etc.” Krachunova (1983: 109-110) concurs, but notes that “this widens the field of medical-genetic counselling with tasks not specific to it” and that such a move is “an attempt to replace existing medical services” which ultimately “makes the help for patients with inherited diseases less qualified.”

The medicalization of disability during state socialism – and the persistence of this medical model after its demise – is a phenomenon

¹⁷ SA – Sofia, F. 2243, Inv. 15, a. u. 9, p. 10.

whose harmful effects have been repeatedly discussed (Mladenov, 2018; Mladenov, Dimitrova, 2012). Genetic counselling adds another touch to this picture, revealing how such medicalization begins even before birth. In the absence of alternative models and voices, the medical narrative remains the only legitimate one, generating a situation of epistemic deficits.

"Prophylaxis" of Disability: Governing Risky Futures

As already mentioned, within the framework of socialist healthcare, genetic counselling was considered a component of "genetic prophylaxis" aimed at "combating the spread of hereditary and chromosomal diseases" (Tsoneva, 1984a: 316). This activity had several main tasks: "1. Genetic prognosis; 2. Limiting births in cases of severe and incurable hereditary diseases; 3. Restricting marriages between heterozygous carriers of severe hereditary diseases; 4. Limiting consanguineous marriages; 5. Introducing [...] modern methods of diagnosing, preventing, and treating hereditary diseases" (Tsoneva, 1976: 37). The well-known from this period ritualistic mobilization of comparisons of socialist and capitalist realities, which was also "a major aspect of health propaganda" (Schmidt, 2024: 10), was invariably applied to genetic counselling in Bulgaria. In the socialist context, genetic counselling was defined as a much larger-scale activity than the "bourgeois-capitalist" one, which remained confined within the family and was "passive". Socialist genetic counselling, by contrast, was active: "a comprehensive activity of searching out, diagnosing, and dispensarizing the identified sick people and carriers" (Tsoneva, 1984b: 14-19), with "the ultimate aim [...] of taking appropriate measures to prevent or limit the creation and birth of sick and defective children" (Ibid., 11-13).

The key practice that made genetic prophylaxis effective was prenatal diagnosis, which enabled detecting fetal defects before birth and, consequently, undertaking abortion for medical reasons: "In the work of genetic counselling, prenatal diagnosis is the most effective tool for reducing hereditary diseases and defects in the population, and hence for reducing infant mortality, disability, and disturbed reproduction. Therefore, knowledge of its possibilities and indications for its application is the duty of every physician and a necessity for the widest range of the population" (Georgieva, 1988: 58). In this way, "the question of protecting the family and society from the birth of sick children is radically solved" (Tsoneva, 1986: 107).

As mentioned above, there were no available epistemic resources at that time that would allow for questioning the notion that disability is solely a misfortune to be eliminated. Across the literature – textbooks, monographs, scholarly articles, popular pamphlets – from the late socialist period, disability is invariably framed as misery, threat, suffering, and burden. As is typical in socialist rhetoric, military metaphors are frequently used: prophylaxis is described as a “fight”, and genetic counselling teams are referred to as “strategic units” (Tsoneva, Zlateva, Kolev, 1987: 124). The family and society, in turn, must be “protected” from “defective, crippled, and imperfect children” (Tsoneva, Genkova, 1976: 87). The emphasis on society and the quality of the population plays an important role in framing these practices. The economic burden of chronic illness and disability is consistently highlighted: “These children are not only a misfortune for the family but also a burden for society, which supports and must support special institutions for their care, rehabilitation, education, etc. All of this requires a lot of resources and care [...]. These hundreds of prevented misfortunes have a considerable effect on society as well” (Tsoneva, 1984a: 318-319).

In 1987 cystic fibrosis, a rare and incurable genetic disease affecting the exocrine glands but not cognitive abilities, was discussed in a collective work. During the socialist period – and in Bulgaria, long after its end – it was classified as a childhood disease due to the lack of appropriate care necessary for ensuring longer life expectancy. Regarding its incidence, statistics for 2024 indicate that approximately 280 people in Bulgaria have cystic fibrosis. It can be reasonably assumed that during late socialism, this number was smaller due to the even lower life expectancy and less effective case detection and diagnosis. However, the economic argument remained central:

In the overall assessment of the social problems associated with cystic fibrosis, the economic problems must be highlighted. The state provides large funds and there are substantial costs for the hospitalization, treatment, and social support of patients and their families. Naturally, [providing] care for affected individuals and families is an inescapable duty of our health service and society. The general strategy with regard to cystic fibrosis as a health, social, and moral-ethical problem should focus on limiting this disease in our population through the active and effective implementation of the methods of medico-genetic counselling and prenatal diagnosis. (Tsoneva, Zlateva, Kolev, 1987: 143).

Another objective indicator highlighted is infant mortality. As Maria Tsoneva (1984a: 318-319) notes, this is "an indicator of enormous health and social importance for every society" and prenatal diagnosis "guarantees [its] real reduction". Doetz's research on the history of genetic counselling in the GDR reveals a similar framing, emphasizing the "improvement of the nation's health as well as a reduction in infant mortality" (Doetz, 2017: 406).

By the mid-1980s, alongside this argument, concerns about escalating genetic risk and the need for its more adequate management had begun to emerge as a rationale for intensifying "prophylactic interventions":

Recently, there has been an increase in the relative proportion of malformations and other congenital diseases [...]. Mastering this pathology is an additional reserve for lowering infant mortality and reproductive failure. For this purpose, early detection of patients, provision of medical-genetic counselling, and application of prenatal diagnosis in future pregnancies in at-risk families are necessary.¹⁸

Such considerations are quite unambiguously reminiscent of the arguments traditionally advanced in favour of eugenic practices. It should be stressed that socialist rhetoric was relatively favourable towards the eugenic project in its basic aim of improving the health and "quality" of populations, although its capitalist "perversions" were always noted. In Maria Tsoneva's writings, we see a largely positive view of "[eugenics'] rational and scientific essence" which, she argues, can be developed "under conditions of social and economic equality of man" (Tsoneva, Genkova, 1976: 96). In her view, "there are dark pages in the history of eugenic teaching that have discredited the concept" (Tsoneva, 1984a: 317-318). However, they "cannot divert the attention of geneticists and sociologists from the search for a scientifically and morally sound regulation of these problems in the interests of the whole society and the individual" (Tsoneva, 1980: 34).

As Victoria Schmidt (2024: 10) aptly notes, "eugenic ideas softly passed through socialist filters", whereas the same cannot be said for "the increasingly complex concept of disability". In Bulgaria, for example, Vassil Prodanov – recognized as one of the country's first bio-ethicists – unequivocally questioned the reproductive autonomy of persons with disabilities. More specifically, he argued that it should be subordinated to the collective interest:

¹⁸ SA – Sofia, F. 2243, Inv. 15, a. u. 8, p. 20, "Plan of the Department of Medical Genetics in Honour of the 13th Congress of the BCP", 1986.

According to some data, about 20 percent of the people on Earth should not have offspring because they would be genetically disabled, which, in the long term, deteriorates the overall genetic stock of humanity. Once it is known that reproduction poses certain dangers, [such a person] should have a sufficient sense of responsibility to refuse to have genetically related children. This, in turn, requires that the corresponding biosocial value be actively asserted through public opinion and various mechanisms of personality education. (Prodanov, 1988: 237-238).

In such a general normative context, it is quite clear that the principle of non-directiveness could not guide genetic counselling. While it was officially endorsed in the WHO's 1969 report on genetic counselling, in Bulgaria – just as in the GDR, for example – “human geneticists [...] deviated from the report's suggestions [...] in their beliefs that counsellors should give a clear recommendation to their patients” (Doetz, 2017: 411). Bulgarian medical geneticists used the phrase “giving advice” (Tsoneva, 1976: 37; Lalchev, 1988: 27), and statements like “the final decision always belongs to the family” were rare (Lalchev, 1988: 27).

Maria Tsoneva formulated the basic dilemma as follows: “Does the physician in the genetic counselling office have the moral right to ‘suggest’ a certain solution to the patient, or should he limit himself to mere enlightenment?” (1984a: 312-313). What is special in this practice, she asserts, is that

the person who comes to the medico-genetic counselling room is not ill in the ordinary sense of the word, but is passing on a hereditary disease to his children [...]. This specificity of the task determines the great responsibility of the patient and the doctor towards the future individual [...]. The future child whose fate is being decided is not yet born, but society is indirectly involved in the decisions concerning its birth [...]. In solving these problems, both doctor and patient are responsible not only before their own consciences but also before society. (Tsoneva, 1984a: 312)

Maria Krachunova further emphasizes the possibility that medical information may not be adequately understood. However, her concern is not that this could undermine real informed choice, but rather – that the affected families might underestimate the risk. The counsellor should, therefore, do everything possible to ensure a genuine understanding of the information provided, namely “the essence hidden behind one or two numbers” (Krachunova, 1983: 119). This essence, in her view, is most effectively explicated through the notion of *cost* – the burden that will be borne upon the birth of a “sick offspring”. The cost

is "relatively low when the disorder is so severe that it ends in intrauterine or early infant death, or when the disease is long-lasting but only slightly impairs normal bodily functions. The burden will be the heaviest, and the cost the highest, in conditions that begin in childhood or young adulthood and lead rapidly to severe disability, combined with a relatively normal life expectancy. Such are, for example, oligophrenic conditions and schizophrenia" (Krachunova, 1983: 119). She then directly recommends that, depending on the family's resources – such as education, intellectual level, and family climate – the counsellor should tailor the way this cost is presented, i.e., "present the same risk in different forms – emphasizing either the 75% chance of giving birth to a phenotypically healthy child [...] or the high genetic risk of 25%" (Krachunova, 1983: 120). This sharply contrasts with the pro-information approach mentioned in the first section, which values and respects the lived experience of disability, particularly in revealing its non-medical aspects. Conversely, Krachunova (1983: 121) explicitly stresses that it may be advisable to meet with families who have a patient with the same disease as the expected one, especially when there is a tendency "to underestimate the risk".

It is important to note, however, that the rejection of the principle of non-directiveness in genetic counselling in the socialist context was additionally motivated by the socialist notion of the physician's duty towards patients. As Tsoneva (1984a: 313) states, "In the conditions of socialist society, the doctor must assist the patient in choosing a solution." In other contexts – for example, in psychiatry – the phrase often used was that the doctor "should not abandon" the patient to face their suffering alone.¹⁹ Undoubtedly, this attitude could be interpreted as paternalistic. At the same time, however, we should not forget that the radical shift towards individual autonomy in medical settings has been convincingly criticized for eroding good care and relationships of trust – precisely by abandoning the patient to their "right to choose" when they are too vulnerable, simply unable, or reluctant to exercise it (Mol, 2006; Conly, 2013). Or as Onora O'Neill (2003: 49) puts it, "When we are patients, we are not well placed to exercise any very demanding form of autonomy." Unfortunately, in the case of socialist genetic counselling – which was so strongly motivated by ableist attitudes – this otherwise beneficial departure from radical autonomist approaches led to too easy justification of selective abortions.

¹⁹ See, for example, Dimitrova (2021) for an exploration of the negative effects of this type of attitude, particularly in relation to service users in the field of mental health.

Conclusion

As an expanding sociotechnical system, reproductive genetics cannot avoid centrifugal effects, i.e. shaping environments and subjectivities – a process that is also called more broadly “genetization” (Lippman, 1992). In this sense, successful technological networks and the actors circulating within them design “not only devices but societies within which these devices might be successfully located” (Bijker, Law, 1992: 12). In this paper, I have attempted to show the introduction of the tools of reproductive genetics into the late socialist context in Bulgaria – which, until this point, had been “technologically innocent” in this respect – and the efforts of experts to apply and affirm these tools as broadly as possible – or, literally, to design societies. This did not happen until 1989, not only because such processes unfold slowly but also due to insufficient resources – people, infrastructure, and equipment. The gradual cultivation of subjectivities embracing the selective package of reproductive genetics continued after the demise of socialism in Bulgaria, maintaining the basic tenets of socialist rhetoric while further benefiting from the intensifying processes of (neo-)liberal responsabilization (Dimitrova, 2012). Unfortunately, what remains unequivocally intact is the entirely positive framing of the “prophylaxis” of genetic diseases and disability through selective abortions. The continuing absence of disability activism, which challenges this strategic substitution, has led to the sheer normalization of the simplistic perception of selective abortion as a means of maximizing health, while portraying life with disability as a life not worth living.

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